Rehabilitation and Choosing a Rehabilitation Facility

Q: Which health care professionals will assist with rehab?

In addition to having a primary care physician who is familiar with the specific needs of your condition, you may require a team of specialists to ensure you remain in good health. A rehab center should have a multidisciplinary team of doctors, nurses and therapists on hand to assist in your recovery. Your rehab team should include a physiatrist (a doctor who specializes in rehab medicine), specialized rehab nurses, various therapists (see box on page 2) as well as case managers, psychologists, social workers, family counselors and discharge planners. Depending on your specific injury, the types of physicians you may encounter include: emergency room doctors, trauma surgeons, neurosurgeons, neurologists, orthopedic surgeons, pulmonologists, cardiologists, urologists, nephrologists, gastroenterologists, plastic surgeons, ear, nose and throat specialists, psychiatrists, palliative care specialists, and maxillofacial surgeons.

Q: How long will I be there?

With the rapid changes and advances in rehabilitation, it is important to do your homework to find the best care for your specific diagnosis. Ideally, your rehabilitation should focus on physical, emotional, and other treatments that will help you return to your community. The goal of rehabilitation is to maximize your neurological recovery while improving your general health and wellness. Rehabilitation is also an opportunity to educate yourself and/or your caregiver about your injury and care. The goal is to develop greater independence and improve your quality of life.
There are many variables that determine the length of your rehabilitation stay for spinal cord injury (SCI). Some physical factors, such as the severity of your injury, your participation and progress in rehab, and the type and intensity of the rehabilitation program, will impact the length of participation. Other factors such as insurance coverage, your ability to pay for costs not covered by insurance, and specific rehab center guidelines may also impact how long you can remain in an inpatient program.

**Q: How many hours a day of rehab will I receive?**

There are two types of rehab: inpatient and outpatient. For most patients, rehab begins with inpatient rehabilitation. An inpatient program may be more intense than an outpatient program. An outpatient program may be more moderate and continue for weeks or months. There are many factors that contribute to your rehab schedule. In the outpatient setting, depending on your specific goals and financial situation, you may participate in rehabilitation up to six hours a day, several days a week.

**Q: What are my options for outpatient rehabilitation care?**

There are a few types of facilities that can be explored as you are leaving your acute care hospitalization. Many people go to a model SCI facility which specializes in inpatient SCI care and may also offer extended outpatient care. A second option would be to go to a CARF-accredited facility with a SCI designation which may be closer to your home. These facilities may or may not have an extensive outpatient program. A third option is to go to a community-based rehab facility. This can include facilities such as the Reeve Foundation sponsored Community and Wellness facilities or your local hospital. Finally, many people transition home and then go to a free-standing OT/PT center in their community for rehab for a certain amount of hours per week. The staff at these facilities may not have specific SCI expertise but can provide basic rehabilitation support.

While inpatient facilities offer 24-hour support and intensive care to assist in your recovery, outpatient facilities usually offer less intensive daily support while you continue to live at home. Usually the more patients a facility treats, the higher the expertise level of the staff. However, there are many other factors to consider in choosing a facility including your specific needs, distance from your home, insurance coverage, ability to pay what insurance does not cover, accreditation, staff-to-patient ratios, support services and outcome results.
Q: How do I select an outpatient facility?

There are many considerations involved in choosing the best and most appropriate care for your condition. In addition to treatments and programs offered, you will need to consider staff-to-patient ratios, and any personal preferences as well as financial and location alternatives. One of the best ways to locate an accredited rehab facility is through the independent, non-profit Commission on Accreditation of Rehabilitation Facilities (CARF) (http://www.carf.org/home/). CARF promotes outcomes-driven, value-based services and accreditation is only awarded after an in-depth review. Be sure to search for CARF-accredited spinal cord injury facilities rather than general care facilities. You may want to look for model SCI facilities (https://msktc.org/sci/model-system-centers). NIDILRR awards SCI Model Systems Center grants to institutions that are national leaders in medical research and patient care and provide the highest level of comprehensive specialty services, from the point of injury through rehabilitation and re-entry into full community life. It is always best to visit the facilities you are considering in order to make the most informed decision.

Depending on your insurance benefits, rehab services may be provided by physical and occupational therapists at your home for a period of time. These services are temporary and are meant to help you transition to an outpatient therapy center. Rehab services depend on medical necessity, level of injury and ability to eventually go to an outpatient therapy center. If your insurance only covers a limited number of visits a year, you may be able to find alternative low-cost options to therapy in your community.

Q: What kind of rehab can I do myself once I am home?

It is important to maintain core strength to be able to sit in a chair and transfer properly. Outpatient therapy visits are often limited by your insurer so here are some other options: local gyms, recreation centers, community colleges or rehabilitation centers with accessible equipment, pools, activity-based therapy, personal trainers, and adaptive sports or recreation programs. The Reeve Foundation’s NeuroRecovery Network® (NRN) also offers cutting-edge clinical centers and community fitness and wellness facilities specializing in activity-based therapies.

Q: What do I need to plan for in the future to stay healthy?

Staying active and fit is important for both the mind and the body. From scuba diving and sailing to basketball and billiards, there are a great variety of recreational and adaptive sports available to explore your interests while spending time with family and friends. By creating a plan that regularly includes activity, you will not only gain a nice break from your typical routine, you can also reduce stress and improve your overall health and wellness. Take the time to research the recreation and fitness options in your community. If you are living with high-level quadriplegia, you can look into using adaptive equipment to resume or try bowling, fishing and hunting amongst other sports. Try to explore paved trails in your chair to get out in nature.
Q: I feel like I’m ready to drive again, what steps do I need to take?

Before you leave your inpatient rehab facility, ask your OT if you are ready for driver training. You may be able to take your adaptive driving training while in inpatient rehab if they offer it. A Certified Driver Rehabilitation Specialist (CDRS) can evaluate if or when it is appropriate for you to drive again as well as the specific modifications and driving equipment to accommodate your needs. The evaluation generally consists of both a clinical and behind-the-wheel assessment. You should visit your state Department of Motor Vehicles to review the licensing process. Your medications may impact your ability to drive so it is important that you speak to your physician about your desire to drive. To find a local qualified CDRS, call a local rehabilitation center or contact the Association for Driver Rehabilitation Specialists (https://www.aded.net/). The American Occupational Therapists Association (https://www.aota.org/Practice/Productive-Aging/Driving/driving-specialists-directory-search.aspx) provides a searchable directory of OTs that evaluate driving. After your evaluation, you can work with a local qualified car dealer to understand modification options and costs. If you are looking to return to your job, vocational rehabilitation offices in your state may be able to help you with the modifications needed to the vehicle—though not with the cost of the vehicle itself.

Sources: Craig Hospital, American Occupational Therapists Association (AOTA) and Commission on Accreditation for Rehabilitation Facilities (CARF), Christopher & Dana Reeve Foundation/Craig Hospital Transition to Home booklet

Choosing a Rehabilitation Facility

Once a spinal cord injury is stabilized, it is important to find the right rehab facility to meet the level and type of care for your condition. It can be a difficult and confusing process but remember that this is a key step in your continued recovery. Take time to research and assess what you think you need and want, then evaluate each option based on your individual circumstances.

Q: Where should I start to research my options?

A facility with accredited expertise is preferable to a general rehabilitation program. One of the best ways to locate an accredited rehab facility is through the independent, non-profit Commission on Accreditation of Rehabilitation Facilities (CARF). CARF promotes outcomes-driven, value-based services and accreditation is only awarded after an in-depth review. Be sure to search for CARF-accredited spinal cord injury facilities rather than general care. The 14 SCI Model System Centers in the U.S. are another good option. National leaders in medical research and patient care, these model facilities provide comprehensive services, from the point of injury through rehabilitation and reentry into full community life. The Reeve
Foundation’s NeuroRecovery Network® (NRN) also offers cutting-edge clinical centers and community fitness and wellness facilities specializing in activity-based therapies.

Q: What criteria or selection process should I use to pick a rehab center?

Many factors need to be considered in choosing the best and most appropriate care for your condition. Use the list of questions above as a starting point. In addition to treatments and programs offered, you will need to consider any personal preferences as well as financial and location alternatives. Whether your next step is inpatient or outpatient care, it is always best to visit the rehab centers you and/or your family members are considering in order to make the most informed decision. Locating specialized pediatric or teen programs is more difficult and you may need to travel further to find one.

Q: What resources do rehab facilities offer?

First and foremost, you want to be sure a rehab center has experience and expertise in your specific needs and condition. A center should have a multidisciplinary team of doctors, nurses and therapists on hand to assist in your recovery. Your medical rehab team should include a physiatrist, specialized rehab nurses, and occupational, respiratory and physical therapists. Other rehab professionals may include psychologists, family counselors, and recreational and vocational therapists.

Q: How do I apply to get into a rehab center?

Patients are often referred for admission directly by their physician, case manager or family member. Medical and insurance information is then requested and reviewed. Many rehab centers have admission counselors or liaisons to assist in the process.

Q: What if my health insurance company won’t cover the rehab facility we think is best?
You may have to pay more if the rehab center you choose is out of your insurance provider’s network. Ask your hospital case manager if they can help you advocate for the unique benefits your desired rehab provides. You can always ask your insurance company to consider an out-of-network exception by doing a single case agreement. (A single case agreement means the exception is only for you and you are not asking them to change their policy for everyone.) This would be an option if you are appealing a denial. Ultimately your choice may be dictated by what your insurer approves unless you can afford to pay the difference in out-of-network fees.

**Q: What if my family member has a dual diagnosis of spinal cord injury and brain injury?**

There are a few facilities that focus on both brain and spinal cord injury. Check the model facility lists for both spinal cord injury and traumatic brain injury. Specialized treatments in cognitive rehabilitation are vital to successful spinal cord injury rehabilitation.

Sources: CARF, Model Systems Knowledge Translation Center

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**Need to talk to someone?**

Our Information Specialists are available to answer your questions.
Call toll-free 1-800-539-7309 Mon-Fri, 9 am-8 pm EST.
Schedule a call or ask a question online at [https://www.ChristopherReeve.org/Ask](https://www.ChristopherReeve.org/Ask)

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**Resources about Rehabilitation**

**American Academy of Physical Medicine and Rehabilitation (AAPM&R)**
[https://www.aapmr.org/](https://www.aapmr.org/)
9700 West Bryn Mawr Avenue, Suite 200
Rosemont, IL 60018-5701
Phone: 847-737-6000
Email: [info@aapmr.org](mailto:info@aapmr.org)
AAPM&R is the national medical society for more than 6,400 physicians specializing in the field of physical medicine and rehabilitation (physiatrists). The site includes a searchable database of physicians (located under the Patients & Family tab).

**American Physical Therapy Association (APTA)**
[https://www.apta.org/](https://www.apta.org/)
1111 North Fairfax Street
The main membership organization for physical therapy professionals, furthering the prevention, diagnosis and treatment of movement dysfunctions. The site includes a searchable database of member physical therapists.

**American Occupational Therapy Association (AOTA)**
http://www.aota.org/
6116 Executive Blvd., Suite 200
North Bethesda, MD 20852-4929
Phone: 301-652-6611
AOTA advances the field of occupational therapy through standard-setting, advocacy, education, and research.

**American Congress of Rehabilitation Medicine (ACRM)**
https://acrm.org/
11654 Plaza America Drive, Suite 535
Reston, VA 20190
Phone 703-435-5335
Email: info@ACRM.org
ACRM is an organization of rehabilitation professionals dedicated to serving people with disabling conditions by supporting research that promotes health, independence, productivity, and quality of life and that meets the needs of rehabilitation clinicians and people with disabilities. Members include physicians, psychologists, rehabilitation nurses, occupational therapists, physical therapists, speech therapists, recreation specialists, case managers, rehabilitation counselors, vocational counselors, and disability management specialists.

**Association of Rehabilitation Nurses**
https://rehabnurse.org/
8735 W. Higgins Rd., Suite 300
Chicago, IL 60631-2738
Phone: 800-229-7530 (Toll-free)
E-mail: info@rehabnurse.org
ARN promotes and accredits rehab nurses and promotes the philosophy of care of the nursing professional.

**Association of Rehab Nurses: ReStart**
https://restartrecovery.org/
This site was created by rehabilitation nurses who understand the special needs of people who experience a major injury, chronic illness, or disability. Rehabilitation provides a total approach to treatment and long-term care for people on the road to recovery. This site covers what to expect while in a rehab facility including transitioning out of the facility and various financial and legal considerations. See their “Making the Right Decision for Rehabilitation Care” booklet also for more on inpatient rehab versus home care options.
National Rehabilitation Association (NRA)
https://www.nationalrehab.org/
P.O. Box 150235
Alexandria, VA 22314
Phone: 703-836-0850 or 1-888-258-4295 (Toll free)
NRA's mission is to provide advocacy, awareness and career advancement for professionals in the fields of rehabilitation. Members include rehab counselors, physical, speech and occupational therapists, job trainers, consultants, independent living instructors and other professionals involved in the advocacy of programs and services for people with disabilities.

Resources for Rehabilitation—Choosing a Facility

CARF International (Commission on Accreditation of Rehabilitation Facilities)
http://www.carf.org/home/
6951 East Southpoint Road
Tucson, AZ 85756
Phone: 520-325-1044, 888-281-6531 (Toll-free voice/TTY)
E-mail: med@carf.org for medical rehabilitation
CARF is an independent, not-for-profit accrediting body promoting quality, value, and optimal outcomes of services through a consultative accreditation process that centers on enhancing the lives of the persons receiving services. CARF establishes customer-focused standards to help providers measure and improve the quality, value, and outcomes of their services. CARF has accredited more than 3,500 organizations in the United States, Canada, and Sweden in the areas of Adult Day Services, Assisted Living, Behavioral Health, Employment and Community Services, and Medical Rehabilitation. CARF develops and maintains practical and relevant standards of quality for such programs.

To locate an accredited rehabilitation facility near you contact CARF. They have information on rehab facilities accredited in spinal cord injury, brain injury, and pain management. The CARF website has a provider search tool at http://carf.org/advancedProviderSearch.aspx where you can look for rehab programs by location (18 countries). You can also narrow the focus by program type, program focus (including Brain Injury Spinal Cord System of Care), and/or age group or special population served.

CARF Canada
http://www.carf.org/Programs/CARFCanada/
501-10154, 104 St NW 1 Yonge St, Suite 1801
Edmonton, AB T5J 1A7, Canada  Toronto, ON M5E 1W7, Canada
Phone: 888-281-6531 (Toll-free)  Phone: 888-281-6531 (Toll-free)
TTY: 520-495-7077  TTY: 520-495-7077
National Rehabilitation Information Center: Spinal Cord Injury Model Systems
https://acl.gov/programs/research-and-development/model-systems-program
The ACL’s National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) funds 14 Model Spinal Cord Injury Facilities in the U.S. Model SCI Centers across the United States work together to demonstrate improved care, maintain a national database, participate in independent and collaborative research, and provide continuing education relating to spinal cord injury. The current model systems are funded from 2016-2021. The current model systems in SCI are:

University of Alabama – Birmingham, AL
Rancho Research Institute – Downey, CA
Craig Hospital – Englewood, CO
University of Miami – Miami, FL
Shepherd Center – Atlanta, GA
Rehabilitation Institute of Chicago – Chicago, IL
Spaulding Rehabilitation Hospital/New England Regional SCI – Boston, MA
Kessler Foundation – West Orange, NJ
Mount Sinai Hospital – NY, NY
Case Western Reserve – Cleveland, OH
Ohio State University – Columbus, OH
Thomas Jefferson University/Magee Rehabilitation Hospital – Philadelphia, PA
University of Pittsburgh, Pittsburgh, PA
Memorial Hermann – Houston, TX

Model Systems Knowledge Translation Center (MSKTC)
https://msktc.org/
MSKTC is a national center that works to put research into practice to serve the needs of people with traumatic brain injuries, spinal cord injuries, and burn injuries. The site lists contact information for the 14 model SCI centers in the U.S. https://msktc.org/sci/model-system-centers

Shepherd Center’s Factsheet: Spinal Cord Injury—Questions to Ask When Selecting a Rehabilitation Program
https://www.shepherd.org/files/wysiwyg/file/Choosing%20Rehabilitation%20SCI(3).pdf

Shepherd Center’s Factsheet: How to Choose a Brain Injury Rehabilitation Program
https://www.shepherd.org/patient-programs/brain-injury/choosing-a-facility

Resources for Rehabilitation—Choosing a Pediatric Facility

CARF (Commission on Accreditation of Rehabilitation Facilities)
http://carf.org/advancedProviderSearch.aspx
Under Age Group you can click on “Children and Adolescents” or “Pediatric Specialty Program”
Christopher & Dana Reeve’s NeuroRecovery Network (NRN) Pediatric Centers
https://www.christopherreeve.org/research/our-rehabilitation-network/nrn-clinical-centers
The NRN centers offer intensive activity-based therapies to promote functional recovery and improved health and well-being for people living with paralysis. They are open to those individuals with a complete or incomplete cervical or thoracic spinal cord injury who have some muscle tone in their legs and a lesion above T12.

- Frazier Rehab Institute, Pediatric Rehabilitation, Louisville, KY Email: Kim Atkinson, KimberlyAtkinson@kentuckyonehealth.org
- Children’s Hospital of Pittsburgh of UPMC, Pittsburgh, PA Email: Meg Stanger, Meg.Stanger@chp.edu
- St. Mary's Hospital for Children, Bayside, NY Email: Sonali Loboda, SLoboda@stmaryskids.org Phone: 718-281-8987

International Center for Spinal Cord Injury (ICSCI) at Kennedy Krieger Institute
https://www.kennedykrieger.org/patient-care/centers-and-programs/international-center-for-spinal-cord-injury
707 North Broadway
Baltimore, MD 21205
Phone: 443-923-9200
Email: info.sci@spinalcordrecovery.org
The International Center for Spinal Cord Injury (ICSCI) at Kennedy Krieger Institute was founded on the philosophy that individuals with paralysis can always hope for recovery of sensation, function, mobility, and independence, months and even years after injury. To maximize on this potential for recovery, ICSCI offers an intense, medically-supervised therapy program with a unique focus on Activity-Based Restorative Therapy. ICSCI was one of the first facilities in the world to combine innovative research with a unique therapeutic focus on restoration and rehabilitation for both children and adults with acute and chronic spinal cord injuries and disorders, including individuals who require the use of a ventilator. They offer an inpatient program for individuals under the age of 22, outpatient programs for all ages, and have been accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF). Most insurance plans are accepted.

Shriners’ Hospitals for Children: Locations
https://www.shrinerschildrens.org/en/locations
Chicago, Philadelphia, and Sacramento are the three Shriners’ hospitals that specialize in spinal cord injury rehabilitation.

The information contained in this message is presented for the purpose of educating and informing you about paralysis and its effects. Nothing contained in this message should be construed nor is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider. Should you have any health care related questions, please call or see your physician or other qualified health care provider promptly. Always consult with your physician or other qualified health care provider before embarking on a new treatment, diet or fitness program. You should never disregard medical advice or delay in seeking it because of something you have read in this message.

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